

June 20, 2016

TO: MT CFHHS Interim Committee. SRJ 22 Study: Guardianship/Alzheimer's Disease Statement in support of LCCF3, LCCF4, LCCF5, LCCF6, and LCCF7

FROM: Kathleen Burke, 1590 Babcock Blvd, Billings, MT 59105

Committee members, individuals who recommended my statement, and audience members, thank you for participation in this ground-breaking day of Alzheimer's support activities. My name is Kathleen Burke and I appreciate that the Montana legislature is considering issues faced by Alzheimer's families through support of Montana's Alzheimer's and Dementia State Plan and the bills of SRJ 22.

Of the top six causes of death in the nation, dementia related diseases are the only ones that cannot be prevented, cured, or even effectively treated. Dementia places substantial emotional, physical, and financial stress on affected individuals, their family members, and our entire society. Projections for Montana Alzheimer's diagnoses are for an increase of 42% by 2025, a timeframe during which we need to derail this startling forecast by changing how we respond to this devastating disease.

I am particularly familiar with caregiving for people with Alzheimer's and related dementias. Unfortunately, I have a family history of Alzheimer's and related brain disorders on both sides of my family for at least two generations, including grandparents, both parents, aunts, and uncles. I helped my maternal grandparents in the 1970s and my parents from 2002 to 2014. In addition, I have been involved with caregiver support groups in Billings for 14 years, so I interact with many people who face the challenges of being family caregivers. I also continue my mother's caring legacy as a member of the Montana Alzheimer's/Dementia Work Group, which, together with the Governor, unveiled the Montana state plan earlier today. One important tenant of that plan is for caregivers to advocate for state and federal acknowledgement and assistance, hence my participation today in support of SRJ 22. It is with a humbling sense of responsibility that I hope to bring a common face to the needs of the 49,000 family caregivers of the current 19,000 Montana Alzheimer's patients.

Shortly after her diagnosis, while walking ahead of me through department store aisles and without stopping or turning around, Mom commented that she hoped that she would die of a heart attack before she became such a burden on the family. She was a nurse, so she knew what upcoming devastation to expect. She asked me to help remind her to cooperate when being assisted in the future.

I would call Mom daily to ask if she had taken the pills set up for her and if she was dressed. I started to find chewed gelatin pills in the garbage and on the floor. One day she wore two shoes of different colors, whereas another time she had on two right loafers. One night when I saw her limping and asked why, she didn't know. I took off her shoe and found a sock crammed in the toe of the shoe. Dad was angry when I suggested he had to pay more attention when helping her. His typical responses were, "She was so smart that I never thought anything like this could happen to her and You don't understand."

Mom was baking a frozen pizza for supper, with the plastic wrap still on it. She said she always did it that way. Since it was no longer safe for her to cook and Dad didn't know how, I had to problem-solve the meals issue.

As my mother's dementia progressed and my father was trying to take care of her at home, my brother was concerned about the toll it was taking on Dad's health. When Dad had a brain abscess in 2007, I had to take Mom to work with me because I could not safely leave her alone. It was difficult to find senior day care in Billings then, it is still limited, and may require a contract as opposed to meeting drop-in needs. The client has to be quite independent, but it is cheaper per day than the \$25-\$30 per hour for in-home care, another good respite option. For parts of Montana that have neither option to consider, family caregivers are required. The caregiver education to be provided by the bills will be very beneficial. At almost every caregiver support meeting I have attended in the last 14 years, caregivers were crying, as they were at the town hall meetings conducted by the Montana Alzheimer's/Dementia Work Group. 85% of family caregivers say they need some kind of respite for their own health and to be better caregivers. Many middle-aged caregivers are the sandwich generation, trying to care for both their own children and their parents, in addition to working full time. I had to find in home help and senior day care. I appreciate public service ads on television about the Montana Lifespan Respite Coalition. I support the proposed bills that will also include volunteer training to provide caregivers for families.

92% of Montanans want to remain at home as long as possible, which is where 77% currently reside. I agree with data showing patients do better at home with support, since unfamiliar places and different routines can add to their confusion. The bill to increase the number of Medicaid service waivers will be of great assistance to the families in providing caregiving at home or in assisted living.

My parents found it increasingly difficult to cope without much oversight, but my brother and I could not easily cover all their needs while working full time. They were accepted into the Program of All-inclusive Care for the Elderly (PACE) a partner program available in over 30 states for approximately 40 years. It met my parents' care needs with services both at home and with medical partners so they didn't have to go to a nursing home until later. They participated in the two year Montana program, which was then eliminated. Bill LCCF3a suggests that additional sources of public and private funding be secured for sustainability. I strongly recommend that reinstating the PACE program be considered. It should also include partnering with the Veteran's Administration, since Montana has such a high number of veteran residents.

In closing, thank you Committee members for being attentive public servants by listening to my testimonial support of the SJR 22 group of five bills. I hope these bills are the beginning of legislative ways to help Alzheimer's families cope with the impacts of this devastating disease before the terrible Montana dementia forecast becomes a reality.